

Enhanced Nursing Care for Improving the Self-Efficacy & Health-Related Quality of Life in Patients with a Urostomy

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Background: Bladder cancer is the most predominant cancer of the lower urinary tract and is the most common cause for urostomy or urinary diversion. Urostomy immensely affect the patient's everyday life from minor physical activity to social relations. Nurse-led interventions have been evaluated for improvement in quality of life in patients with urostomy.

Objective: The main objective of this study was to review the medical literature in a systematic way to evaluate the nursing role in improving the health-related quality of life of patients undergoing urostomy.

Methods: A systematic search of the PubMed, CINAHL, Embase, and Science Direct databases was carried out to identify studies that have evaluated the effect of nurse-led intervention on the self-efficacy and health-related quality of life in patients with urostomy. In addition, studies for factor affecting the quality of life were also investigated.

Results: Overall, 10 studies were identified as suitable for inclusion in this review. Health-related quality of life was lower in these patients as compared to population norms and several factors such as age, employment, and living status were identified as the contributing factors. Preoperative education was critical in meeting the psychological needs while postoperative intervention was instrumental in improving the self-efficacy and health-related quality of life particularly when a continued nursing-patient interaction was existent.

Conclusion: A comprehensive nurse-led intervention consisting of preoperative and postoperative components aimed at ostomy-related education, psychological counseling and compliant with patient factors is feasible and may result in greater improvement in self-efficacy and health-related quality of life in patients with urostomy. Larger clinical trials are warranted to validate these results.

Keywords: bladder cancer, nursing, urostomy education, quality of life, perioperative care

Introduction

Stoma is a surgical opening of an organ to communicate with the outside of the body to facilitate the excretion of waste products (faeces or urine) from the body.¹ Ostomy is usually performed in patients with malignancy and other benign conditions, such as trauma, obstruction, ischemia, and inflammatory diseases.^{2,3} The most common types of stoma include the colostomy, ileostomy, and urostomy; and the most common causes for these ostomies in respective order are colorectal cancer, inflammatory bowel disease and bladder cancer.^{3,4} Bladder cancer is the most predominant cancer of the lower urinary tract and depending on the presentation its therapeutic management may involve surgery (transurethral resection or radical cystectomy), radiation therapy, chemotherapy, and immunotherapy in the form of immune checkpoint blockade and intravesical immunotherapy also termed as BCG (bacillus Calmette-Guérin).⁵⁻⁷ Radical cystectomy is offered when bladder cancer invades the muscle wall and is termed as muscle-invasive bladder cancer (MIBC).⁵⁻⁷ In such instance, a urinary diversion or urostomy is created for urine to leave the body.^{7,8} Urinary diversions are of three types including incontinent conduit (IC), continent cutaneous diversion (CCD), and orthotopic neobladder (ONB).⁸ In incontinent conduit (IC), urine is emptied into an ostomy bag via a stoma on the abdominal wall while an intermittent catheterization of the stoma is required in the continent cutaneous diversion (CCD). In ONB surgery

involves the creation of a pouch in the pelvis constructed from a portion of the small bowel and anastomosed to the urethra to allow normal micturition.⁸

Urostomy, or stoma in general, immensely affect the patient's everyday life from minor physical activity to social relations.⁴ Various factors, such as loss of control over the urine elimination, pouch leaks, bad odor, flatulence, not only can negatively influence the self-esteem and confidence of the patients but also compromise the social well-being.^{9–12} Moreover, proper functioning needs continued care for several physiological reasons including skin inflammation, electrolyte imbalances, stoma necrosis and parastomal hernias, and retraction or prolapse.^{13,14} In a study interviewing 11 patients living with urostomy identified six themes that described their perception of the major concerns including 1) surgery impact, 2) body image, 3) daily and social-life activities, 4) stoma and sexuality, 5) managing stoma education, 6) family and friends' support.¹⁵ Hence, enhanced nursing care and nursing-patient interaction based on the scientific research is essential to assist these patients and achieve a better quality of life. To address this issue, we have carried out a systematic review of the literature to highlight the recent updates in the nursing management of urostomy and reflect on the progress in this regard.

Methods

This systematic-review and meta-analysis was carried out following the updated version 2020 of PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines ([Supplementary Table 1](#)).¹⁶

Eligibility Criteria

Target Population and Treatment

Patients with urostomy who were administered with preoperative or postoperative nursing care or nurse-led education programs.

Outcome of Interest

Main outcome of this study included the improvement in the self-efficacy or quality of life of patients with urostomy. Other outcomes included individual and treatment-related factors adversely affecting the quality of life for which studies published between 2012 and 2022 were considered.

Study Design and Language Restrictions

Only studies with prospective, cross-sectional, and descriptive designs, as well as, randomized clinical trials were included. Studies with retrospective designs, case studies, conference abstracts, letters to the editor, literature reviews, and systematic reviews and meta-analysis were excluded. Only studies published in English were included.

Research Strategy and Study Selection

PubMed, CINAHL, Embase, and Science Direct were formally searched with several key terms until June 30, 2022. The following search terms were used singularly or in combination in all fields: “urostomy”, “urinary diversion”, “nursing care”, “nursing-led education program” and “quality of life” ([Supplementary Table 2](#)). Further potential studies were identified through screening references of relevant articles. A step-wise procedure comprising retrieving, organizing, and screening was followed by two reviewers to select studies meeting the eligibility criteria. Disagreements were solved after mutual consultation.

Data Extraction and Synthesis

Characteristics of the included studies and attributes of participants were extracted that included first author, publication year, study design, number and type of participants, details of intervention and quality of life assessment. Participants' attributes included age, gender, disease type, married status, and type of urinary diversion. The extracted data were transformed into a table form.

Results

Initial database search with key terms identified 562 studies. Interestingly, PubMed database search with key term “urostomy” only identified 342 studies. The number of studies per year on the topic only reached to a maximum of 24 studies in 2021 ([Figure 1](#)). Screening for title and abstract and duplicates removed 552 studies. Further scrutiny for eligibility criteria resulted in the final selection of 11 studies (n = 871) including 5 randomized controlled trials (RCT) for qualitative analysis ([Figure 2](#)).

PUBMED SEARCH - UROSTOMY

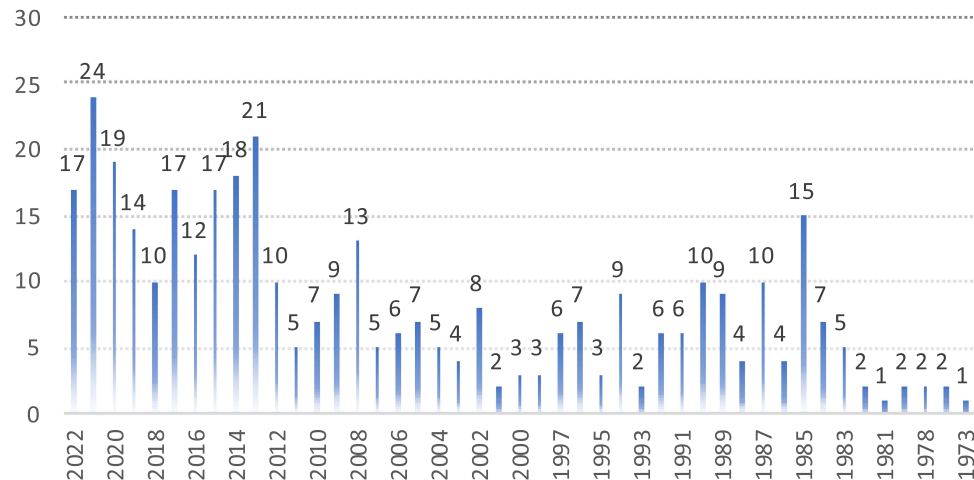


Figure 1 PubMed search outcome with key term "Urostomy" from 1973 to 2022.

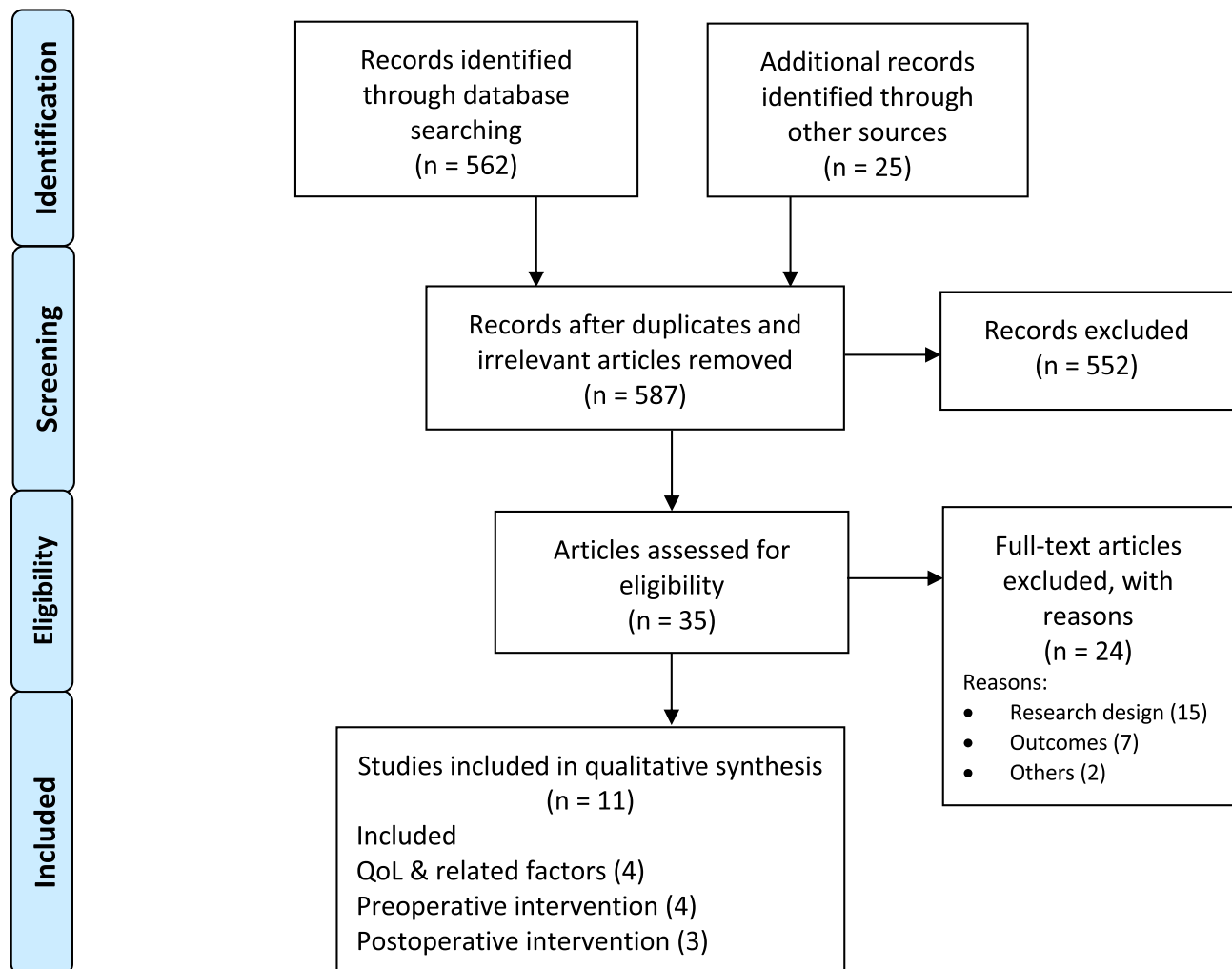


Figure 2 Research strategy and study selection.

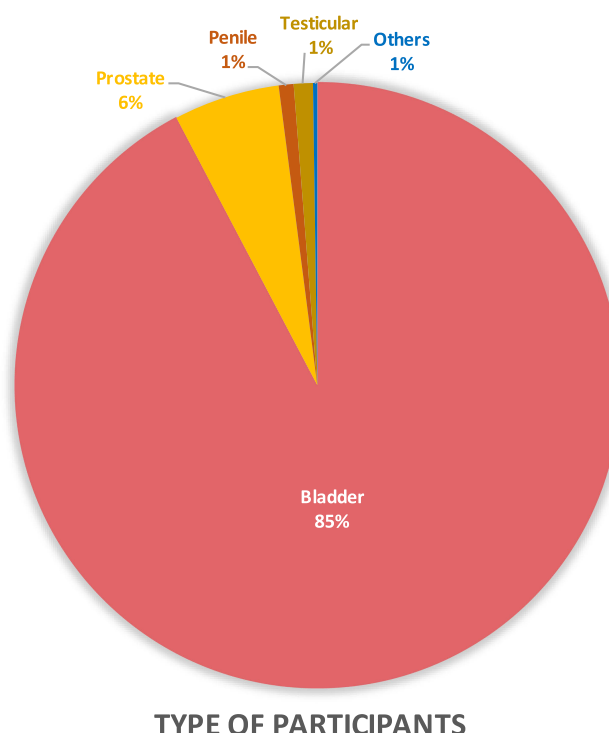


Figure 3 Primary disease of the participants.

Bladder cancer patients constituted the majority of the participants (85%) followed by prostate cancer (10%) (Figure 3). The most common type of urinary diversion was the construction of an ileal conduit (91%) followed by neobladder (4%) (Figure 4). Male was the predominant gender type constituting between 71% and 93% of the study participants. Mean age ranged between 63.25 and 73.6 years old. Detailed characteristics are outlined in Table 1. Characteristic details of intervention and assessment are summarized in Tables 2 and 3.

Factors Affecting Health-Related Quality of Life (HRQOL)

Assessment of quality of life in patients living with a urostomy is an essential tool to determine the overall level of satisfaction of the patients with the treatment (surgical procedure and nursing care), and, in doing so, could also identify the various factors that are negatively affecting their health-related quality of life. Moreover, determining the patients' problems can provide essential assistance in designing appropriate nursing approaches and education programs. A cross-sectional descriptive study involving 24 patients with urostomy, who were interviewed at least four months after urostomy, revealed that life-style factors affected by urostomy included dressing habits (83.4%), sleep patterns (91.7%), family life (91.7%), participation in social activities (91.7%), and occupation (75.0%).¹⁷ Body image and sexual relationship were identified as the main concerns in these patients. Health-related quality of life, as determined by EORTC-QLQ-C30 scores, demonstrated lower mean scores for general wellness, functional condition, and symptomatic condition domains (54.16 ± 15.29 , 44.07 ± 9.62 , and 64.31 ± 12.56 , respectively) in comparison to the population-based norms.¹⁷ Age (>65 and ≤ 65 ; Symptomatic condition: 67.20 vs 55.98 ; $p < 0.05$), working status before operation (Yes and No; Functional condition: 46.37 vs 41.77 ; $p < 0.05$), and living status (alone, wife, and wife and children) had significant influence on the functional condition and symptomatic condition domain of the EORTC-QLQ-C30. Patients living alone performed better on symptomatic condition domain as compared to those who were living with their spouse or spouse and children both (mean scores: 75.42 versus 67.09 versus 50.64 ; $p < 0.05$). A rather opposite situation was apparent for the functional condition domain of the EORTC-QLQ-C30 (mean scores: 31.85 versus 42.07 versus 44.29 ; $p < 0.05$).¹⁷

Another study conducted in Japan also reported HRQOL in patients living with urostomy based on the 8 domains of the Medical Outcomes Research Short Form 36, version 2 (SF36v2).¹⁸ Only the body pain domain exceeded the mean 50 score

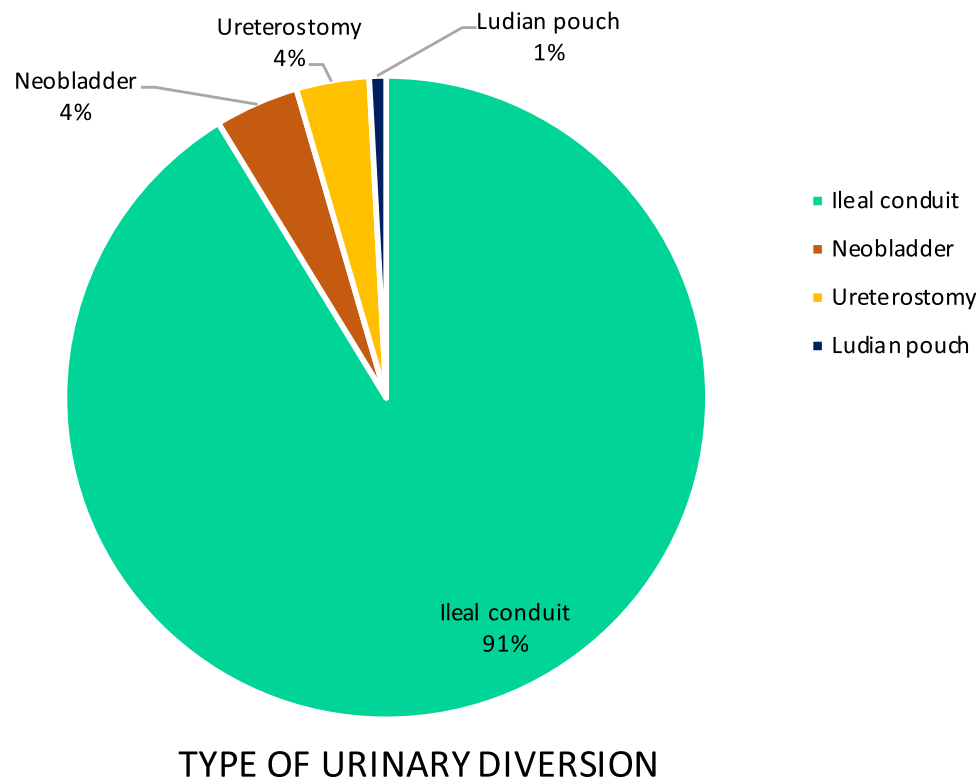


Figure 4 Type of urinary diversion constructed for participants.

(standard mean score) indicating better quality in this domain. Bladder cancer patients undergoing urostomy reported significantly higher score on the social function domain compared to urostomies performed for other causes (47.8 ± 9.8 vs others 35.7 ± 10.8 ; $P < 0.01$). Significantly lower mental health domain score was associated with presence of a support person at home (yes: 41.8 ± 8.8 vs no: 46.9 ± 8.1 ; $P < 0.05$), and participation in ostomy support groups was associated with a lower score on body pain domain (yes: 47.4 ± 11.7 vs no: 53.9 ± 7.4 ; $P < 0.01$). In this study, duration from the surgery was identified as a significant factor affecting the patient's quality of life. In comparison to patients living with urostomy for more than four years, patients with urostomy who had surgery during the last four years demonstrated significantly lower health-related quality of life scores (role physical: <4 years: 42.9 ± 10.2 vs >4 years: 8.4 ± 9.7 , $p < 0.05$; vitality: <4 years 45.3 ± 8.1 vs >4 years 50.4 ± 7.9 , $p < 0.01$; role emotion: <4 years 42.8 ± 10.0 vs >4 years 48.8 ± 9.0 , $p < 0.001$).¹⁸ Similarly, HRQOL assessed with Stoma–Quality of Life questionnaire by telephone 6 months after urostomy surgery was ranked as good by 95% of the participants (mean score 68.54, range 64–73).¹⁹ It appears that the patients with urostomy interviewed within short period of time following urostomy demonstrate a low HRQOL. Correspondingly, global health status/quality of life (GHS/QoL) was recovered to pre-hospitalization level at 6 months (T2) after an initial decline at 2 weeks after surgery (T1) in a study involving bladder cancer patients undergoing urostomy and neobladder (GHS/QoL: T0: 71.61 ± 20.89 ; T1 62.91 ± 19.98 ; T2: 75.66 ± 19.12).²⁰ Overall, a general improvement in the HRQOL and global health status/QoL from T0 (1 month before surgery) to T2 was demonstrated ($p < 0.001$).²⁰ It is suggested that patients face difficulty in the early post-surgery period in adjusting to the new life but with time they acquire knowledge, expertise and acceptance permitting them to more independence.²¹ Nonetheless, patients were in contact with nurse during these 6 months and 32 out of 35 respondents (91.4%) contacted or visited the ostomy nurse's office at least once, which may have had a positive impact on their life quality as well.¹⁹ Moreover, distinct questionnaires were used in these studies which may have an impact on the overall outcome of these studies.

Preoperative Nurse-Led Interventions

There have been very few studies on the efficacy of nurse-led education interventions programs in the management of bladder cancer patients with urostomy. A qualitative study aimed at improving the self-management and post-ostomy life of bladder

Table I General Characteristics of Studies and Participants

First Author and Year	Study Design	Sample Size (Exp/Con)	Country	Setting	Age (Exp/Con; Years)	Male (%)	Married (%)	Bladder Cancer (%)	Ileal Conduit (%)
Pazar, B. et al (2015) ¹⁷	Cross-sectional descriptive	24	Turkey	Hasan Kalyoncu University, Gaziantep, Turkey	63.45 ± 6.33		22 (91.6)	23 (95.8)	
Furukawa, C. et al (2013) ¹⁸	Cross sectional questionnaire by interview	60	Japan	Municipal hospital, Osaka, Japan	72.1 ± 9.04*	43 (71.7)		54 (90)	47 (78.3)
Gomez, A. et al (2014) ¹⁹	Cross sectional questionnaire by phone interview	54	Spain	Hospital Clinic, Barcelona, Spain	69.75 ± 9.51*			54 (100)	54 (100)
Masiero, M. et al (2021) ²⁰	Observational study of patients and caregivers	382	Italy	European Institute of Oncology, RCCS, Milan, Italy	67.29 ± 9.23	319 (82.9)		382 (100)	
Wulff-Burchfield, E. M. et al (2021) ²²	Qualitative, descriptive	29	United States of America	University of Kansas Medical Center, Kansas City, KS, USA	70.75 ± 10.68*	22 (76)	24 (82.8)	29 (100)	29 (100)
Ali, N. S. and H. Z. Khalil (1989) ²³	Randomized controlled trial (RCT) with Pretest-posttest design	30	Egypt					30 (100)	
Zganjar, A. et al (2021) ²⁴	Longitudinal Quality Improvement feasibility study	51	United States of America	University of Kansas Medical Center, Kansas City, KS, USA	72.2 ± 8.65	38 (75)		51 (100)	51 (100)
Jensen, B. T. et al (2017) ²⁶	Randomized controlled trial (RCT)	107 (50/57)	Denmark	Aarhus University Hospital, Denmark	68.5 ± 9.8/ 70.6 ± 9.2	79 (76)	63 (58.9)	107 (100)	92 (85.9)
Merandy, K. et al (2017) ²⁷	Randomized controlled trial (RCT)-two-arm pilot study	8 (4/4)	United States of America	New York Presbyterian Hospital/ Weill Cornell Medical College in New York, USA	73.6 ± 14.08*	8 (100)		8 (100)	5 (62)
Hao, H. et al (2022) ²⁸	Randomized controlled trial (RCT)	80 (40/40)	China	Affiliated Hospital of Nantong University, Nantong, P.R. China	64.8 ± 12.58 / 63.25 ± 17.16		66 (82.5)	19 (23.7)	
Zhou, H. et al (2019) ²⁹	Randomized controlled trial (RCT)	46 (23/23)	China	Shanghai Pudong Hospital, affiliated with Fudan University Pudong Medical Center, Shanghai, China	65.04 ± 11.61/ 66.13 ± 11.01	43 (93)	36 (78.2)	46 (100)	46 (100)

Note: *Estimated mean and standard deviation from median and range or interquartile range.

Abbreviations: Exp, experimental group; Con, control group.

Table 2 Outcome Assessment and Main Findings

Study	Assessment Method	Time Points of Assessment	Outcome Measure	Instrument	Main Findings
Pazar, B. et al (2015) ¹⁷	Physical interview and mail response	At least 4 months after urostomy.	Impact of urostomy on daily life activities, Health-related quality of life (HRQOL)	A research-based self-prepared questionnaire (37 questions) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire version 3 (EORTC QLQ-C30)	Body image, sexual problems were the main identified factors Lower HRQOL compared to population-based norms Age, employment, and living status had significant impact on HRQOL
Furukawa, C. et al (2013) ¹⁸	Physical Interview	At least one month after discharge and 3.4 years (median time) since surgery	Health-related quality of life Impact of patient factors on HRQOL	Medical Outcomes Research Short Form 36, version 2 (SF36v2)	Surgery timing (role physical, vitality, and role emotion domains), employment (role physical domain), support at home (mental health domain), and belonging to peer support groups (body pain domain) had significant impact on certain domain of SF36v2.
Gomez, A. et al (2014) ¹⁹	Telephonic interview	6 months after urostomy	Health-related quality of life	Stoma-Quality of Life questionnaire (20 Qs)	High quality of life percentage
Masiero, M. et al (2021) ²⁰		1 month before surgery, 2 weeks and 6 months after surgery	Psycho-emotional wellbeing Global Health Status (GHS) HRQOL	Emotion thermometer (ET) EORTC QLQ-C30	Improved GHS/QoL and psycho-emotional wellbeing at 6 months
Wulff-Burchfield, E. M. et al (2021) ²²	Physical interviews	3 to 18 months	Educational and psychological impacts Identification of themes	Self-prepared questionnaire	Anxiety was reduced and confidence was boosted Three themes were identified, 1) motivation was provided by lack of knowledge, fear, and concern; 2) Attitudes included acceptance and dependence; 3) Education
Ali, N. S. and H. Z. Khalil (1989) ²³	Telephonic interview	Before discharge and 3 rd postoperative day	State anxiety	A-state form of the State Trait Anxiety Inventory	Significantly lower state anxiety on the third day postoperatively and before discharge Main anxieties were related to being cancer patients and the impact of surgery on their bodies and on their social and marital life.
Zganjar, A. et al (2021) ²⁴	Physical interviews	At enrollment/discharge, 2-week (OAS), 6-week and 12-week	Health-related quality of life Ostomy-specific adjustments during the study	SF36v2 The Ostomy Adjustment Scale (OAS)	Improvement at 6-week in HRQOL that persisted a 12-week OAS level at discharge was maintained at 6- and 12-week assessment
Jensen, B. T. et al (2017) ²⁶	Physical interviews	At day 35, 120 and 365 postoperatively	Self-efficacy	Urostomy Education Scale	Improved self-efficacy observed in the intervention group.
Merandy, K. et al (2017) ²⁷	Physical interviews		Self-efficacy Feasibility and self-care skills	Six-item Self-Efficacy to Manage Chronic Disease (SES6G) scale Exploratory self-efficacy (ESE) question Urostomy Education Scale (UES) (for incontinent UD) An exploratory continent UD scale (ECUDS) (for continent UD)	No difference in self-efficacy was noticed between the cohorts Feasibility was noticed
Hao, H. et al (2022) ²⁸	Telephonic interaction	Three months after discharge	Social stigma Quality of life	Social Impact Scale (SIS) Quality of life scale for cancer patients (QLQ-C30)	Social stigma was significantly lowered and quality of life was enhanced in the intervention group
Zhou, H. et al (2019) ²⁹	Physical and telephonic interaction	At discharge and 6 months post-surgery	Self-efficacy Health-related quality of life	Stoma Self-Efficacy Scale (SSES) and the City of Hope Quality of Life-Ostomy (COHQOL-O)	Improvements in the intervention group were noticed in terms of self-efficacy and HRQOL.

cancer patients was carried out by Wulff-Burchfield et al at the University of Kansas Health System (KUHS) Urology Department.²² The Stoma Bootcamp (SBC) education program, developed by a team of specialists including a urology nurse practitioner, an ostomy nurse, and a project coordinator, comprised of important components such as psychosocial care, pre-operative timing, and lay and peer teachers with the goal of improving patients' and caregivers' abilities to care for the stoma physically and psychologically. Overall, 16 patients, 18 caregivers and 3 program educators completed the interviews from 3 to 18 months post-program. In general, the SBC program was well received and termed as effective and timely by patients whose expectations of post-ostomy life were transformed from anxiety to that of confidence. Unfortunately, no quantitative data was provided regarding the efficacy of the education program. Nonetheless, lack of knowledge, fear and concern about the procedure were cited as motivation for the education program participation, which suggest the need for such programs to

Table 3 Intervention Details

Study	Point of Intervention	Intervention Provider	Duration of Intervention	Frequency	Program Format
Wulff-Burchfield, E. M. et al (2021) ²²	Prior to surgery	A urology nurse practitioner, an ostomy nurse, and a project coordinator	2-hour Stoma Boot Camp	Once preoperatively	<ul style="list-style-type: none"> Lecture, audiovisual presentations, hands-on activities with pouching supplies, use of an anatomical model to illustrate the surgical procedure, use of a soft stoma doll for take home use with younger family members. The presence of a patient advocate – a previous SBC attendee who served as a model of post-ostomy life, answered participant questions, and demonstrated what a stoma looked like on a real person. A stoma product manufacturer's representative was also present to answer questions. Take home materials included an illustrated booklet of the content, sample pouching supplies from a manufacturer's representative, the stoma doll, and a DVD of stoma-related information.
Ali, N. S. and H. Z. Khalil (1989) ²³	1–2 days prior to surgery			Once preoperatively	<ul style="list-style-type: none"> Ostomy education A visit by a peer with an ostomy Time to express concerns and anxiety about the procedure
Zganjar, A. et al (2021) ²⁴	Within 2 weeks of the surgery date	Advanced practice providers, residents, ostomy nurses, research staff, floor nurses, and a patient advocate.	3-hour Stoma Boot Camp	Once preoperatively	<ul style="list-style-type: none"> A short audio-visual presentation by residents and advanced practice providers that reviewed the definition of an ostomy, the operation itself, recovery and expectations for their post-operative care. Ostomy nurses then demonstrated basic urostomy care – pouching, sizing, emptying – with hands-on supply kits that patients/care-givers could practice with and take home. Additionally, the ostomy nurses reviewed trouble-shooting tips for common ostomy problems (irritated skin, barrier not sticking, bleeding, stoma prolapse/retraction), and expectations for normal daily living (showering, exercise, sleeping, clothing, swimming, sexual intimacy). Supplemental information consisted of additional online written and video resources regarding their ostomy care, postoperative expectations, and follow-up information. During their hospitalization the stoma boot-camp patients were given the standard postoperative education – typically three education sessions with 1–2 pouch changes prior to discharge.
Jensen, B. T. et al (2017) ²⁶		Two Urological Enteral Stoma Therapy Nurses (ET)		Once preoperatively	<ul style="list-style-type: none"> The two ET's introduced and instructed the intervention group to basic stoma care and change of appliance using a training kit with an artificial stoma. The patient was informed about the urostomy and life with a urostomy related to the individual patient's life and life style. Every patient had a follow up prior to surgery where the ET observed self-care skills regarding stoma care and change of appliance.
Merandy, K. et al (2017) ²⁷	Delivered on postoperative day 4, 5, or 6	Clinician, wound ostomy and continence nurse (WOCN)	One-hour	Once postoperatively	<ul style="list-style-type: none"> A simplified medical illustration of participant-specific UD A step-by-step UD self-care instructional video, and a pictorial Microsoft PowerPoint®.
Hao, H. et al (2022) ²⁸	Over 3 months	3 attending physicians, 5 nurses, and 2 recovered patients		Continued interaction	<ul style="list-style-type: none"> Nurses provided routine nursing and health education before and after surgery for the urinary system cancer and after discharge from the hospital The physicians were responsible for surgical planning and follow-up of the pre-inpatients Using the message function on the WeChat public account, the responsible nurses promptly completed the postoperative pipeline maintenance and stoma nursing care to provide professional help and promote patients with active treatment in the intervention group. Patients helped each other and tidied over difficulties Empathy counseling and psychological adjustment Family support
Zhou, H. et al (2019) ²⁹	Over 6 months	1 WOC/enterostomal therapy nurse and 3 RNs with specialized training in ostomy care		Continued interaction	<ul style="list-style-type: none"> Routine care included ostomy-related education preoperatively and at discharge delivered to both cohorts. The multicomponent intervention included a health record for every individual that focused on the patient's self-management, recovery from ostomy surgery, ostomy care skills, diet, psychosocial assessment, stoma or peristomal complications, and pouching problems. Participants attended lectures given by the ostomy care team monthly, which included a pouching demonstration, emphasize on the importance of their participation in the patient's physical care and the need of ongoing emotional support, and at least one family member attended the lecture in person. A physical assessment and care were performed by the ostomy care team. A telephone call monthly from a member of the ostomy care team wherein the patient and family members were encouraged to discuss challenges with pouching, any stoma or peristomal complications, diet, lifestyle, physical activity, and psychosocial status. Patients and families were also encouraged to attend an ostomy support group held quarterly.

be performed preoperatively as well. In coherence with the first study, an RCT with pretest-posttest design conducted by Ali and Khalil involving Egyptian patients with urinary diversion demonstrated quantitative evidence of benefit in the postoperative anxiety levels in the experimental group at discharge and on day 3 postoperatively ($p < 0.05$).²³ The study also identified the main anxiety contributors, which included being cancer patients and the impact of surgery on their bodies and on their social and marital life. The study was aimed at assessing the effects of a preoperative psycho-educational training program on the postoperative anxiety levels, which consisted of ostomy education, a visit by a peer with an ostomy, and time to express concerns and anxiety about the procedure. These outcomes indicate that preoperative stoma education programs can successfully lower the anxiety levels of the patients by improving their knowledge about the procedure and self-management.

A recent longitudinal and quality-improvement feasibility study performed at the University of Kansas Health System evaluated the efficacy of a preoperative “stoma boot camp”, a 3-hour group session within 2 weeks of the surgery date, on the health-related quality of life of bladder cancer patients scheduled for radical cystectomy with ileal conduit formation (RCIC).²⁴ The education content included a short presentation regarding the procedure, recovery and expectations for their post-operative care by residents and advanced practice providers. Moreover, basic urostomy care was demonstrated by ostomy nurses that comprised of pouching, sizing, emptying and trouble-shooting tips for common ostomy problems. The patients ($n = 51$) achieved an average ostomy adjustment score (OAS) of 150.4 (95% CI 142.0, 158.8) at discharge which showed no decline over a 12-weeks duration. Numerical improvements in the Short-form 36 (SF-36) scores were also observed in each category at 6 week which persisted at the 12-week mark. Although the categorical scores were higher to published population norms (for SF-36 scores for US general population), the study lacked a direct control group and hence no comparative efficacy superiority of the program can be established.²⁵ In a recently concluded RCT, bladder cancer patients in the intervention group showed a significantly better stoma self-care (2.7 [95% CI: 0.9; 4.], 4.3 [95% CI: 2.1; 6.5] and 5.1 [95% CI: 2.3; 7.8] at day 35, 120 and 365 postoperatively) measured on “The Urostomy Education Scale” as compared to standard.²⁶ In their study, the intervention group was instructed to a preoperative standardized stoma-education program that consisted of areas recognized necessary to change a stoma appliance. This is the first study to report a positive efficacy of a short-term preoperative stoma intervention based on the RCT-design.

Postoperative Nurse-Led Interventions

Postoperative efficacy of nurse-led education programs has been well established in stoma patients; however, there were not many studies in the urostomy cohorts evaluating the postoperative efficacy. In a two-arm randomized controlled trial, self-efficacy (SE) or self-care in patients with bladder cancer requiring urinary diversion (UD) was investigated based on the intervention of a supplemental multimethod educational program.²⁷ Study reported no difference in self-care independence ($p = 0.4286$) between the treatment arms assessed with Six-item Self-Efficacy to Manage Chronic Disease (SES6G) scale, and no change in pre- versus post-SES6G score in the intervention group ($p = 0.125$) was noticed. Only two participants from the control group demonstrated self-care independence in the entire sample. It must be pointed out that the control group was younger in age which further stresses the point that age is an important factor in determining the outcome of such educational programs and must be taken into consideration in designing these educational programs. Nonetheless, feasibility and acceptability were shown for integration of such programs in these patients. Moreover, a need for ongoing post-discharge support and education support was noted. In another randomized controlled trial involving 80 urinary system cancer patients, the effects of a nurse-led education program via an online interactive platform “Wechat” for education of patients with urostomy was evaluated.²⁸ Intervention group was provided with psychological intervention as compared to the control group who received routine nursing care. The Chinese version of social impact and quality of life scales were used which indicated a significantly lower score for stigma ($p < 0.01$) and higher score for quality of life in the observation group ($p < 0.01$). A third randomized controlled trial using the Chinese language versions of the Stoma Self-Efficacy Scale (SSES) and the City of Hope Quality of Life-Ostomy (COHQOL-O) questionnaire assessed the effect of a nurse-led multicomponent intervention on ostomy-related complications, self-efficacy, and health-related quality of life in 46 patients who underwent radical cystectomy with an ileal conduit.²⁹ Results indicated significant decrease in the incidence of complications at 6 months (4.35% vs 30.43%, $P = 0.047$). Additionally, greater self-efficacy in stoma care (107.13 ± 11.87 vs 85.65 ± 12.87 , $P = 0.000$) and higher health-related quality of life (154.48 ± 16.01 vs 138.26 ± 13.42 , $P = 0.001$) were also indicated.

Discussions

In this study, we have reviewed the medical literature in a systematic way to rationalize the need for perioperative care in patients undergoing urostomy in order to improve their health-related quality of life. The literature research yielded very limited results indicating that this particular group of patients is neglected, which stresses the need for more robust attention. Health-related quality of life was lower in these patients as compared to population norms and several factors, such as age, employment and living status, were identified as the contributing factors. Preoperative education was critical in meeting the psychological needs while postoperative intervention was instrumental in improving the self-efficacy and health-related quality of life particularly when a continued nursing-patient interaction was existent.

Our study identified three major essential components for designing a comprehensive nurse-led education program (Figure 5). The main component of ostomy education intervention, which was constant across studies, was the ostomy-related care skills education that consisted of oral and practical presentation.^{22–24,26–29} The results indicated that both preoperative and postoperative intervention are helpful tools in improving the self-care skills and HRQOL in the intervention group as compared to patients receiving routine care.^{26–29} It could be debated whether the combination of two periods might further enhance the outcomes of these interventions? For example, post-operative period is essential as the patients had just undergone the surgery and they might be vulnerable and in need of assistance. Intervention at this stage can improve their confidence and self-care skills; however, patients' compliance can be an issue to select the right window period for intervention.²⁷ On the other hand, preoperative period might be vital as stoma-related care skills could be practiced on a mannequin in advance. In doing so, dexterity of the participants could also be assessed and, hence, vulnerable participants could be identified who need more attention.²⁷ Moreover, patients have demonstrated augmented motivation before the procedure driven by lack of knowledge about the procedure which could further improve participation.²² Therefore, preoperative period can be the right time for ostomy-related educational intervention. Post-operative period can be rather essential for continued care through nursing-patient interaction as has been demonstrated in these studies.^{28–30} In fact, postoperative intervention has been critical in the prevention of stoma-related complications which has shown to affect the HRQOL adversely.^{21,29,30} Moreover, timing of assessment is also critical as early (few weeks) and late (6 months

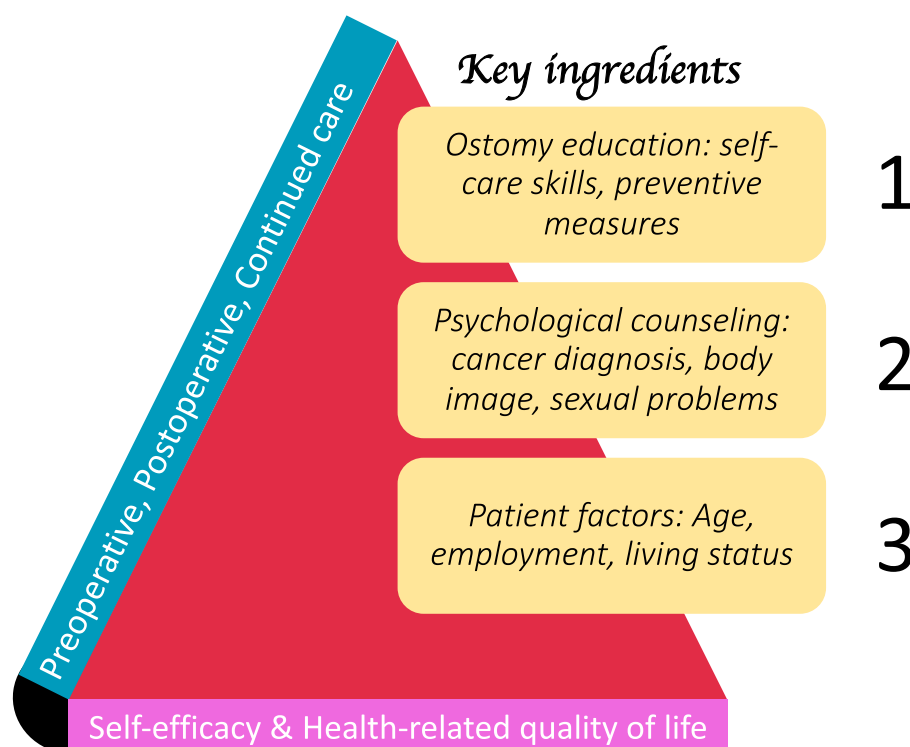


Figure 5 Triangle of Perioperative care for patients with urostomy. Three major ingredients include ostomy-related education, psychological counseling and patient's factors. Point of intervention starts from preoperative to postoperative in the form continued care to enhance the self-efficacy and quality of life in these patients.

onwards) assessment may influence the outcome of interventions.^{18,20} Hence, multiple assessment points may be necessary to measure the efficacy of interventions and further detect inadequacies.

In this study, two main problems that may be alleviated with psychological counseling were the body image and sexual relationship.¹⁷ Body image is the self-perception of one's physical well-being in terms of attractiveness and function and its disturbance can be manifested in the form of dissatisfaction, concern, and distress.^{12,31} Stoma patients have been reported for experiencing a negative body image, particularly in patients with younger age, overweight, and temporary stoma.^{9–12,32} Psychological counseling of the patients and family members in this regard could be an essential tool to cope with the discomfort and boost their self-confidence. In fact, psycho-emotional wellbeing of the caregivers has also been associated with global health status and quality of life of the patients.²⁰ Therefore, improving the psycho-emotional wellbeing of primary caregivers might boost QoL in patients. Another severely affected aspect of urostomy on patients is their dysfunctional sexual life. Sexual problems experienced by the patients include no desire, erectile dysfunction, anorgasmia in female, and even inability to generate a penile erection.^{10,17}

Identification of vulnerable patients who might need special consideration and attention should be carried before the initiation of intervention. Three main factors that were identified contributing to various aspects of the quality of life included age, living status, and employment status. Age (older participants) had significant impact on the patient's dexterity affecting self-care independence but was associated with enhanced acceptance.^{17,21} Age (younger participants) was also identified as contributing factor to the negative perception of body image.¹⁸ Hence, different age groups would require special kind of consideration in terms of education and psychological counseling. Similarly, patients with previous employment may face difficulty in coping with the new life as compared to the ones with no previous employment.¹⁷ Therefore, differential psychological input would be desirable to assist such patients. Living status (alone, with wife, or wife and children) has also demonstrated to differentially affect the outcomes of quality of life scores.^{17,18}

Several factors limit the outcomes of outcomes of our study. The studies included were from diverse geo locations and some consisted of small number of participants. There was no detailed information about the type of urinary diversion. Moreover, distinctive instruments were employed to assess self-efficacy and health-related quality of life. Likewise, the point of assessments also varied from study to study.

Conclusions

Urostomy enormously affect the quality of life which can be improved via preoperative nurse-led personalized education consisting of physical and psychological components with a postoperative continued and planned interactive educational course respecting the patients' needs. Our study emphasizes the need for a comprehensive structured perioperative educational program led by nurses to adequately support the patients with urostomy.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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